

Ladies and Gentlemen, Dear friends

IF, the International Federation for Spina Bifida and Hydrocephalus, is a worldwide network of persons with these conditions and their families or a Disabled people organisation or DPO.

IF, as a Human Right advocate, strives for the right of a decent life, accurate care for these children and adults, all over the world.

This is the reason I am asked to speak about the right to life for children with Spina Bifida and Hydrocephalus.

The **Universal Declaration of Human Rights (UDHR)** was adopted by the United Nations General Assembly in 1948, partly in response to what Nazi's did in World War 2 to minorities like Jews and persons with a disability.

This declaration covers all human beings: women, men, children with or without a disability. For specific groups additional Human Rights Conventions were adopted too like :

- In 1979, the Convention on the Elimination of All Forms of Discrimination against Women
- In 1983 the Convention on the Rights of the Child, and
- In 2006 the convention of the right of persons with a disability.

In addition the WHO adopted in 2010 a resolution on Birth Defects.

Also DPO's like IF, EDF and many others produced their own resolutions on specific issues and matters.

Through the European Disability Forum who took a main role in writing the convention on the right of persons with a disability IF had a say in this convention. This convention has already proved to be an excellent tool for fighting against all forms of discrimination based on disability.

IF as a handicap - specific organisation representing one of the most common birth defects concentrated its efforts since 2000 on access to health and access to life. Being a member of EDF and becoming a member of the International Disability alliance (IDA) IF can relay in many areas on their expertise and work. This enables IF to concentrate on the specific needs our target group is facing. In EDF and IDA IF is complementary.

For this audience and within the available timeframe I will concentrate what these Human Rights Conventions and Resolutions mean for the specific matters involving people with Spina Bifida and Hydrocephalus and their families.

Spina Bifida and Hydrocephalus are a special and important group when it relates to Human Rights. I can compare Spina Bifida with the bird workers in the mines take with them. When the birth dies because of lack of oxygen the miners know they have to go back.

Spina Bifida shows a mirror to the world, I look at this world through the hole in the back of children. I invite you to look with me.

Spina Bifida is a birth defect and is preventable by primary prevention. Spina Bifida and Hydrocephalus are detectable by prenatal screening.

As we know, Spina Bifida cannot be cured, through surgical interventions and lifelong care most people with Spina Bifida now live into old age and have a good quality of life. So medical action is needed from birth or is even possible prenatally.

The more opportunities people with Spina Bifida are given, the more self-confidence they develop, so that they are able to overcome most of their problems and lead a meaningful life. The last decades the treatment and care of children and adults with Spina Bifida has made tremendous progress.

Neurosurgery improved, many children can be treated without a shunt, correct management of the neurogenic bladder from birth on results in children being infection free and dry. Consequently, the quality of life of people with Spina Bifida and Hydrocephalus also has improved considerably.

When I speak to outsiders I mention the diversity in people telling about Albert who is now 90 years old, about Jeffery Tate and Guro Fjellanger, about the family of Heidi and our growing children in Africa, because it is important to inform society about the potentials and abilities of persons with Spina Bifida without ignoring their problems. A society that is not believing in us, will not invest in us. I will come back to this later.

IF concentrates on 4 domains: Human Right, Primary prevention, International solidarity and network development but they are all linked to each other.

The IF mission is to improve the quality of life of persons with Spina Bifida and primary prevention.

In human right IF focusses on access to health and the right to life.

I believe IF has a good story to tell society. All over the world IF and its members fight for primary prevention and for the right to a decent life for all children with Spina Bifida. We believe that our lives are valuable and worthwhile to live. As said the prognosis for a newborn child has never been as good as now.

Research in Norway, the Netherlands and US show that young people living with Spina Bifida quote their quality of life even higher than their peers without a disability.

However it is the poor expected 'Quality of life' that is used over the last decades to promote prenatal screening, termination of pregnancies and more recently even euthanasia in newborns with Spina Bifida.

The most prominent Human Right, the right to life, is questioned related to Spina Bifida.

At our world conference in Toulouse in 2000, IF brought together 270 people with Spina Bifida and their families from 20 different countries to discuss their quality of life experiences.

Amongst these 270 participants there were several university graduates, including an ex-minister who has Spina Bifida, but also people who need permanent support and care.

Together they formulated a powerful resolution, stating that the quality of life with their impairment, the disability they had been living with for 20 or 50 years or longer, is not an argument to propose termination of pregnancy. They asked for a positive and future-oriented approach to babies with Spina Bifida through information, education and emancipation.

This resolution was the basis of a similar resolution within EDF but concerning all prenatal detectable disabilities. It is clear that not the persons concerned but outsiders judge our quality of life as being poor and not worth living.

The person involved is in the best position to judge about his quality of life. Well they did and what they say can not be misunderstood. The disability movement states that their quality of life depends more on an 'acceptant, welcoming society' and environment than that it depends on their impairment. An inaccessible society harms more our quality of life than our impairments.

Here the Convention of the Rights of persons with a disability really helps to fight for a supportive and inclusive society. Conventions and resolutions defend our rights towards an inclusive society with the right to life in all our diversity.

Were with this convention, when adopted and ratified, the fights to be over, medical progress in prenatal imaging questions again these rights.

The womens movement won in most countries right towards a safe legally accepted abortion.

In this discussion IF does not take a radical pro-life position. The disability movement, with a strong lobby of women with a disability, is not against abortion. They worded it as follows: we are defending that a woman has the choice 'not' to be pregnant, but should not have the choice between 'this child' or 'an other child'. Choices based on health, gender, colour of eyes... are questioned.

Indeed termination of pregnancy because the unborn child has a disability differs fundamentally from abortion. An abortion allows a woman to not want to be pregnant, to stop the pregnancy. She refuses a pregnancy. After diagnosis by prenatal screening she refuses a child based upon the knowledge that the child has a disability.

In many countries the legislation on abortion widens the period for a legal abortion if the unborn child has a disability from 13 weeks to 24 weeks when a disability is detected. In most countries termination of pregnancy is unlimitedly allowed if the mother's life is in danger.

If the pregnancy is in a later stage, after 24 weeks, the child could survive out of the womb. To ensure that this does not happen, a lethal injection is administered via the stomach of the mother into the baby's heart.

This happens in many countries even in the eighth or ninth month of the pregnancy. The procedure is clearly described in medical journals and the actual debate in Spain, the Netherlands and Belgium wants to legalise this practice.

The psychological burden for parents to make such a decision is much heavier than with a normal abortion. The life of the unborn child is refused because of a disability. The child was wanted and the mother felt the unborn child.

Where is the right of the unborn child'? The foetus has no legal status. For the law it does not exist and is not covered by legislation.

However courts gave parents and children whose disability was not detected due to a professional mistake financial compensation because they did not get the choice to abort. 'The

wrong life claims' give the unborn child the right to be aborted? If unborn children are given the right not to live, they should also have the right to life.

I do not think that physicians have bad intentions. But medical evolution goes fast and society did not have the time for ethical reflection. The ethical discussion, resulting from new techniques, weights on the shoulders of parents and physicians that are not prepared and trained to handle it correctly.

I felt that parents and physicians are asked to handle an immoral or at least impossible choice.

Within a medical model physicians are trained to cure illnesses. Eliminate disabilities is great when done by primary prevention, but eliminating future Human Beings because of their disability is something else. I believe that the ethical problem becomes bigger the more the unborn child is growing during the pregnancy and the more the foetus becomes a child.

The doctor's suggestion to terminate the pregnancy is called secondary prevention. But it isn't real prevention, it is elimination of an unborn child affected with Spina Bifida.

IF does not blame parents taking such a decision. IF questions the way counseling is done. Often future parents are confronted with one sided negative information on the disability of their unborn child.

Genetical counselling is a difficult and complex matter. Our network wants to cooperate with centres of genetic counselling, gynaecologists and obstetricians to produce tools to facilitate balanced information in their prenatal counselling.

Why is the majority of the parents prepared to continue their pregnancy after their child is diagnosed with a Neural Tube Defect in one centre and in other centres 95 % of the parents terminate their pregnancy? The only difference is the quality of the counselling.

Good counselling should inform parents about the disability and the abilities, about the condition and all possibilities of treatment. Written information for parents is needed and will help them to make their informed decision.

Negative stereotypes on Spina Bifida are influencing prenatal counselling. To ensure that parents are correctly informed on the condition of their child IF produced for the European Conference on preconception care a position paper on prenatal counselling.

The right to life in all your differences is the first and most essential human right. All international treaties and conventions underline this right and mention the right of all available treatment that can improve the life conditions of the individual.

Access to life saving treatment of newborns with Spina Bifida is also in discussion. IF strives for the right of treatment of all newborns with Spina Bifida. IF believes that, according the conventions of the Right of the child, the UN convention of the right of persons with a disability and the WHO resolution on Birth defects, that all children have the right to access all available treatment that can improve their quality of life and prevent further damage.

If treatment is withhold children with Spina Bifida can survive but the disabilities will get worse. Most children develop hydrocephalus and without surgery the head can enlarge so that the neck can not support the head anymore and pressure on the eye nerve will cause blindness.

Without accurate continence management children with Spina Bifida will get pressure wounds and kidney failure.

This we see in many developing countries where the lack of services result in children dying or surviving in inhuman conditions.

The international solidarity of IF where members from the North like Norway invest in their friends of the South resulted in good care of children with Spina Bifida in several developing countries. IF translates the knowledge of the North to the possibilities and means of the South. Only in East Africa IF and its partners have 3000 children with Spina Bifida in neurosurgery follow-up and many more with Hydrocephalus. In total more than 10 000.

IF believes that it is a human right to get the treatment wherever a child is born.

Connected to services in developing countries IF empowers parents and stimulates the establishment of parent groups. These groups can become National or regional organisations and members of IF. This is part of our network development. DPO's are crucial in promoting the Rights of persons with a disability. In developing countries I see NGO's coming and going. Kids and parents remain. Our IF members are voicing the needs on National Level. IF does it Internationally

Last year the WHO voted a resolution on Birth defects calling member states to develop plans and activities to prevent birth defects and improve the care for these people. IF understands prevention as primary prevention.

WHO combines comprehensive guidance, information and awareness raising, with the care for children with birth defects and by fostering the development of parent-patient organizations.

WHO promotes effective interventions to prevent tobacco and alcohol use during pregnancy, ensuring folic acid supplementation.

WHO calls for the establishing genetic services, continued providing care and support to individuals affected by birth defects.

Because only when there is treatment and care available , parents have a real choice.

WHO calls to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedom on an equal basis with other children and give priority to the child's well-being and support and facilitate families in their child-care and child- raising efforts;

However the Right to life saving treatment is also in discussion.

Due to the fact that neonates with Spina Bifida are not dying as such, and as said, no treatment will cause secondary and preventable disabilities a group of physicians in Groningen in the Netherlands, are pleading to legalize active euthanasia in newborns with Spina Bifida.

They documented, in the so-called Groningen protocol, 22 children with Spina Bifida who were killed shortly after they were born with the consent of the Justice Department.

They feel backed by the legislation concerning euthanasia. By expanding this legislation to people who are unable to decide for themselves, they are preparing new legislation which permits the killing of children with an impairment.

James Wilkinson a pro-choice American Lawyer looked from the Human Right perspective at the Groningen protocol and concluded that negative stereotypes on disability play a major role in decision making.

This is also true in societies where treatment is not available.

When IF started in 1993 its work in Africa medical journals stated that the incidence of Spina bifida was nearly zero. Now we know that the incidence is higher than in the North. These children just did not reach the hospitals and the statistics.

When we started to provide services parents came from all over the country. A negative circle, where no treatment leads to a very bad quality of life of these children results in no believe in the future of them. This 'no believe' leads to no investment and no treatment.

Access to care and treatment is essential. It is a Human Right. IF achieved a resolution against the Groningen Protocol stating that newborns with Spina Bifida should have access to all available treatment that can improve their quality of life and prevent secondary disabilities and again this resolution was the basis of a EDF resolution about the right of treatment of newborns with all disabilities.

IF looked at this resolution in light of the WHO resolution on birth defects and commented on the draft.

This resolution adopted at the SIXTY-THIRD WORLD HEALTH ASSEMBLY on the 21 May 2010 urges all member states to organise correct counseling and good support for parents of newborns with a disability

Article 9 states: to take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children and give priority to the child's well-being and support and facilitate families in their child-care and child-raising efforts;

And article 11: to support families who have children with birth defects and associated disabilities, and ensure that appropriate habilitation and support is provided to children with disabilities;

This is a big step forwards because only in a welcoming society parents have the choice to fight for their unborn and new-born children with a disability

In EDF I initiated with Giampiero Griffo a working group on how negative stereotypes on disabilities are barriers towards access to health.

In Uk persons with disability are afraid not to have access to the same life saving health services in life threatening situations.

In Europe Spina Bifida became a rare disease because of elimination and not because of primary prevention. That's why the IF network was hesitating to become a member of Eurodis ,the European network of Rare diseases and did not want to be seen as a rare disease. In Guatemala there is in some regions an incidence of 1 in 150 life births.

But in Europe the reality, figure wise, makes Spina Bifida a rare disease with all problems like orphan drugs, poor access to good care etc...connected to it.

Several hospitals have closed their coordinated care units for Spina Bifida. Research lessened, adult care is rarely available and not developed. Spina Bifida is perceived by many professionals as a solved problem. In Dublin the paediatrician of the Spina Bifida team retired without successor in place. What a tremendous loss of expertise and knowledge!

IF is aware that the expertise build up over the last decades has to be kept available because even as a <rare disease>, Spina Bifida will always occur and children will need treatment and care.

Without accurate care we put the clock 50 years back in time when there was no treatment available and when Spina Bifida was seen as a disability that was not compatible with life. When the belief in our children disappears health services will not invest in our target group.

IF questions termination of pregnancies and advocates for access to treatment and primary prevention.

In primary prevention IF took double action.

IF advocates for primary prevention due advocating for fortification of staple food with Folic Acid and setting up awareness campaigns for supplementation.

IF advocates for mandatory fortification of staple food with Folic Acid especially in countries with a higher incidence.

Food fortification certainly brings a high incidence like in Guatemala to a low incidence.

This can not only be reached by fortification of stable food, it will always be a combination of several methods. Preconception counselling, daily intake of supplements with folic acid, fortification of staple food and further investment in monitoring and fundamental research.

Last but not least 'access to treatment and care' is still not correctly developed for the growing group of adults and ageing persons with Spina Bifida.

Most interdisciplinary services are organised in paediatric settings.

Our adults are often victim of a splintered inefficient health care. This often has dramatic consequences where persons with Spina Bifida die. I see it as a Human Right that they have access to these services.

Governments should work closely with our member associations to ensure access to good care and to society and towards the implementation of the UNCRPD and for unborn and new born children with a disability, the WHO resolution on birth defect.

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